Illinois Department of Children and Family Services

Institutional Review Board Meeting Minutes November 26, 2019

CHICAGO Dr. Margaret Scotellaro

Janet Chandler

ON PHONE Janet Ahern

Tammy Fuller Kim Mann

Arricka Newingham

Rocell Cyrus Robin Albritton Brooke Taylor

CALL TO ORDER

Janet Ahern called the meeting to order at 2:06 p.m. A quorum was present.

APPROVAL OF MINUTES

MOTION: Kim Mann made a motion to approve the minutes October 22, 2019.

Dr. Margaret Scotellaro seconded the motion and a unanimous vote from the remaining board members carried the motion.

FOLLOW UP

Sara Taxman. Non-Suicidal Self-Injury and Childhood Maltreatment among Adolescent Youth in Care.

University does not have data sharing agreement with DCFS. Researcher's professor contacted the IRB coordinator to inquire about obtaining a data sharing agreement with the department. Request sent to legal who indicated that Executive Leadership would need to approve this request. IRB coordinator sent request to Chief of Staff Debra Dyer for a response.

Researcher is unable to determine how they would get the information without a data sharing agreement.

MOTION: Motion made to continue to table the proposal.

NEW PROPOSALS

<u>Julie Crouch.</u> Maternal Depression, Domestic Violence, and Child Development Delays in a Child Welfare Sample.

Researcher is getting data from Integrated Assessment/Northern Illinois University.

She already has access to the IA data – is that included in the data sharing agreement with NIU? She can get de-identified data.

Need IRB from Northern.

Going to use CANS – can de-identify that easily. IA screener will review the record.

Proposed project is already been collected by IA program and has been de-identified.

Board would like to know what the process for getting the de-identified data. They are getting it during consulting activities.

MOTION: Margaret Scotellaro motioned to approve the proposal.

Tammy Fuller seconded the proposed motion and a unanimous vote from the remaining board members carried the motion.

Miranda Honigman. Response to Grand Challenges in Social Work.

What is the process and what is she going to do?

Before goal change for the child – they go through legal screening process.

Even in the event the court changes the goal – still has to go through legal screening.

Researcher will be pass through for all caseworkers before it gets passed on - a pre-screening. Doing this in an internship (new learning).

Lay out a little more data to illustrate what she is going to do – what data will you track that DCFS is tracking. Legal enters to CYCIS.

QI Project. Board would like to see her project proposal to see if more information can be gleaned regarding the requests.

MOTION: Motion made to table the research proposal awaiting requested information.

<u>James Tonsgard.</u> An Intermediate Access Protocol for Selumetinib for Treatment of Neurofibromatosis Type 1 with inoperable, progressive/symptomatic plexiform neurofibromas.

Only concern noted was that a waiver of assent from pediatric patients was being requested. Dr. Scotellaro felt that the youth in care should provide informed assent to enroll in the protocol.

Janet indicated that she would meet with the youth at the next doctor's appointment and ensure that he assents.

MOTION: Margaret Scotellaro motioned to approve the proposal.

Kim Mann seconded the proposed motion and a unanimous vote from the remaining board members carried the motion.

OTHER

Robert Foltz Data Share Request. Sent to Rocell Cyrus for review. It was indicated that this needed to be reviewed and approved at a higher level. Brooke sent to Chief of Staff Debra Dyer for review and response. Brooke will follow up with Debra regarding request.

James Tonsgard MOU. Janet will follow up with researcher's assistant around the exact language needed for the IRB approval letter. She will draft accordingly and have the Director sign.

Margaret Conway Data Request. Brooke sent requested information to Rocell for review. She will get back on what legally can be shared with the researchers.

The December meeting is being cancelled due to the holidays. If proposals are needing to be reviewed, they will be reviewed via email and email voting; otherwise they will be tabled until the January meeting.

The meeting adjourned at 2:49 p.m.